Data, Registry and Surveillance

Cancer is actually a catch-phrase for many diseases with a wide variety of causes. It can result from genetic predisposition, lifestyle choices, environmental factors, or a combination thereof. Many causes are as yet unknown. Cancer in its many forms represents a major public health issue, as well as a significant challenge to measure and record. Public health agencies rely on several types of information to understand cancer: reports, vital statistics, surveys, assessments of potential exposures, and administrative sources.

A national system of cancer registries can help us understand the disease better and use our resources to the best effect in prevention and treatment.

— Dr. Donna Shalala

Cancer surveillance activities in Montana can be grouped into two main categories: morbidity and mortality information, and risk behavior information. The Montana Vital Statistics Bureau and the Montana Central Tumor Registry (MCTR) conduct surveillance of cancer and mortality. Cancer mortality data are gathered from death certificates.

Cancer is a reportable disease in Montana. The MCTR maintains the data management system on the incidence of various cancers, stage at diagnoses, treatments, and outcomes of cancer and other reportable tumors. This system, which has been in existence since 1979, establishes cancer incidence and relative survival rates.

Incident cases — or the count of each tumor occurrence — include information such as diagnosis, stage, and treatment. These are submitted to the MCTR by 60 hospitals, two radiation centers, one Veteran's Administration hospital, three pathology laboratories, and many out-of-state cancer registries. Currently, there is no mechanism to report physician-based cancer cases to the MCTR. Estimates indicate that these cases represent an additional two to three percent of all cancer tumor incidence.

Surveys on health status, risk behaviors, and life experiences of populations are used to capture prevalence data, which can tell us how widespread a given condition is at a specific point in time. Modifiable health-risk behaviors are monitored by the Montana Behavioral Risk Factor Surveillance System (BRFSS). This survey of adult Montanans collects information about a number of health behaviors and preventive practices on a continuous basis. These include tobacco use, nutrition, exercise, healthcare, access, and cancer-screening behaviors.

The Environmental Public Health Tracking (EPHT) project coordinates the collection, integration, analysis, and interpretation of data about exposure to environmental hazards and its effect on human health. The Department of Public Health and Human Services (DPHHS) and the Department of Environmental Quality (DEQ) were awarded federal funding in October 2002 to participate in building a national EPHT network, the ultimate goal of which is to integrate data systems nationwide, so that all sectors of the public can take action to prevent and control environmentally related health effects. Existing surveillance systems yield the baseline rates of disease, mortality, or morbidity necessary to detect disease clusters.

Sources of administrative data, including providers, insurers, hospitals, and local health departments also produce health data that could help highlight cancer risks and trends and enhance cancer control efforts, but these data are not readily accessible. Integrating and sharing these data would improve efforts to plan, evaluate, and craft cancer control policy.

Data can help identify areas where greater efforts are needed, potential causes, and progress toward reducing cancer mortality. Access to complete, timely, and accurate cancer data is critical to our ability to evaluate progress toward comprehensive cancer prevention and control.

Incidence: The number of new cases of a disease diagnosed each year.

Morbidity: Disease, or the incidence of disease, within a population. Morbidity also refers to adverse effects caused by a treatment.

Goal I: Data collected by the Montana Central Tumor Registry will meet the North American Association of Central Cancer Registries (NAACCR) Gold Standard for complete, high-quality, and timely data.

Objective I.1: *Improve reporting of reportable cancer cases to the MCTR within 24 months of the close of the diagnosis year.*

Baseline: Currently, there is 92.1 percent case ascertainment within 24 months of year end (MCTR 2002)

Outcomes: By 2010, increase ascertainment within 24 months of year end to 95 percent

Data sources: MCTR

Strategy 1	Analyze barriers to reporting and utilize physician input and other states' procedures to design a process that will educate healthcare providers and facilitate the reporting of tumors.
Strategy 2	Review other data sources including hospital cancer registrars, physicians' offices, the Office of Vital Statistics, Indian Health Services (IHS), and the Montana Breast & Cervical Health Program (MBCHP).
Strategy 3	Evaluate case ascertainment on American Indian Reservations and develop a mechanism for collecting missing data.
Strategy 4	Review *pathology only* cases and contact primary physicians to obtain reportable data on missing cases.
Strategy 5	Evaluate existing, and develop new, data exchange agreements that encourage other states to collect and provide data to MCTR on Montana cancer patients treated in those states.

Objective I.2: *Decrease the percentage of* race unknown *and* death certificate only *cases reported.*

Baseline: Among reported cancer cases, 4.2 percent are categorized as *race unknown* and 5 percent as *death certificate only* (MCTR 2002)

Outcomes: By 2010, reduce those categorized as *race unknown* to 3 percent; reduce those listed as *death certificate only* to 3 percent

Data sources: MCTR

Strategy 1	Analyze source of *race unknown* and *death certificate only* designations and design strategies for implementation to improve reporting.
Strategy 2	MCTR will request tumor case information from certifying physicians and hospitals where death occurred.

- What is reportable?

All malignant cancers (including in-situ) except basal cell carcinoma or squamous cell carcinoma of the skin

All benign tumors of the brain

All carcinoid tumors

- What is *death certificate only*?

A cancer case reported to the MCTR based on a cancer diagnosis on the death certificate.

- Why is this important?

A high percentage of *death certificate only* cases in the MCTR could indicate under-reporting of cancer cases by hospitals and physicians.

Goal II: Analyze and disseminate cancer-related data.

Objective II.1: *Increase the dissemination and use of Montana Central Tumor Registry data.*

Baseline: The MCTR currently publishes a biennial report
Outcomes: Publish the MCTR report annually and post on the Cancer Control webpage
Data sources: Process outcome results

Strategy 1	Publish and disseminate an annual MCTR report, to include education on MCTR, risk factor data, incidence by tumor type, mortality, and benchmark comparisons. Add to the Cancer Control webpage.
Strategy 2	Regularly assess and disseminate information on the cancer burden in Montana utilizing existing data sources. Identify the need for additional data sources and work toward establishing data links.
Strategy 3	Promote use of MCTR data in cancer research publications. Develop creative avenues to present cancer-related data, such as utilizing Geographic Information Systems (GIS) data maps.

The Montana Central Tumor Registry is the primary cancer-surveillance tool in Montana. The MCTR maintains a data management system that tracks the occurrence and characteristics of cancer and other reportable tumors. It collects information on such things as demographics, staging, treatment, follow-up, and outcomes. The data are gathered for all Montanans regardless of whether or not they were treated here.

Objective II.2: *Increase the cancer cluster information available on the Cancer Control webpage.*

Baseline: The cluster investigation protocol is not widely implemented within DPHHS; cancer cluster information is not available online
Outcomes: By 2008, publish cancer cluster educational information on the Cancer Control webpage
Data sources: Process evaluation results

Strategy 1	Implement and institutionalize the use of the cancer cluster investigation protocol within DPHHS.
Strategy 2	• Produce a Cancer Control webpage that includes cancer cluster investigation reports and educational information. • Link the Cancer Control webpage to the DPHHS health data website. • Incorporate data from the Montana Central Tumor Registry, Montana Breast and Cervical Health Program, and Vital Statistics.

Cancer, in general, is common. According to the American Cancer Society, about 1,399,790 Americans will be diagnosed with cancer in 2006.

Cancer cluster: A statistically significant, greater-than-expected number of cancer cases that occur within a group of people in a geographic area over a period of time.

Goal II: Analyze and disseminate cancer-related data.

Objective II.3: *Improve the availability, accessibility, and utilization of cancer-related data.*

Baseline: There is no cancer-related data resource list; there is no broad-based analysis of cancer using multiple data sources

Outcomes: By 2008, create a cancer-related data resource list; create broad-based cancer analyses; post on the Cancer Control webpage

Data sources: Process evaluation

Strategy 1	Compile a list of cancer-related publications and data resources, and add to the *Cancer Resource Roster* on the Cancer Control webpage .
Strategy 2	Post a link on the Cancer Control webpage to the Centers for Disease Control and Prevention (CDC), Behavioral Risk Factor Surveillance System (BRFSS), and other cancer-related data sources.
Strategy 3	Collect and analyze data on cancer from multiple sources including the MCTR, Vital Statistics, BRFSS, claims, insurance, and admissions data. Identify barriers, gaps, and disparities in the cancer control continuum. Implement interventions to rectify the deficiencies.
Strategy 4	Periodically publish and promote a comprehensive Montana cancer control report. Include updates on the progress of Comprehensive Cancer Control Plan projects.
Strategy 5	Support standardization and integration of databases among Indian Health Service, Montana Breast and Cervical Health Program, the MCTR, the EPHT, and the Rocky Mountain Biomonitoring Consortium (RMBC).
Strategy 6	Utilize and support analyses of BRFSS and American Indian survey data to learn more about risk factors. Add appropriate questions to ongoing surveys as needed for comprehensive cancer control.
Strategy 7	Develop a taskforce to: • support the Comprehensive Cancer Control Program's internal and external data needs. • work with the cancer epidemiologist. • identify gaps, needs, disparities, and barriers in cancer data and determine interventions to rectify the deficiencies.
Strategy 8	Establish new data sources for use in assessing, strategizing, and prioritizing future comprehensive cancer control activities.

Some racial and ethnic groups have higher incidences of, and deaths due to, cancer. Such disparities may be due to multiple factors, such as the late stage of disease at diagnosis, barriers to healthcare access, biologic and genetic differences, health behaviors, cultural differences, exposures to carcinogens in the environment and the workplace, and other risk factors.

"Somewhere, something incredible is waiting to be known." — Carl Sagan

Goal II: Analyze and disseminate cancer-related data.

Objective II.4: *Collaborate with Montana's Environmental Public Health Tracking project to establish integrated databases that allow epidemiological investigations of health hazards from environmental exposures and other sources.*

Baseline: Databases are not currently integrated

Outcomes: By 2011, integrate data sets from the MCTR and the MBCHP; integrate data sets from the remaining agencies listed in Strategy 1

Data sources: Process evaluation results

Strategy 1	Collaborate with the DPHHS Environmental Public Health Tracking project to integrate cancer-related databases, including MCTR, and MBCHP data as well as other existing or emerging sources of environmental or health-related data (e.g., Department of Environmental Quality, data from other DPHHS divisions, the Environmental Protection Agency, Agency for Toxic Substance and Disease Registry (ATSDR), the Occupational Safety and Health Administration (OSHA), and the United States Department of Agriculture [USDA]).
Strategy 2	Support creation of the information technology needed to enhance cancer data collection, as through the Informatics Section of the Public Health Improvement and Preparedness Bureau.
Strategy 3	Increase access to cancer-related data for epidemiological analyses by working with the Health Planning Section of DPHHS to establish a Montana Interactive Health Database website for data analyses.
Strategy 4	Disseminate results derived from a newly established Montana Interactive Health Database to allow comparative analyses over time and establish trends in cancer-related health conditions in Montana for use in assessing progress and making comparative analyses.
Strategy 5	Promote the use of datasets by epidemiologists and public health agencies to improve knowledge, enhance investigations, and create risk-reduction strategies and guidelines for cancer care in Montana.

Timeline for Available Data

Hospitals report abstracted information on cancer patients who are diagnosed and treated, usually after the patient has completed treatment. Treatment can take six months or more. After the cancer case is submitted to the MCTR, the case is entered into the MCTR database and checked for quality. Over 100 data variables are checked for consistency and validity. Sometimes, hospitals need to be contacted for more information. Yearly data are not available for about 12 to 18 months after the year-end, so hospitals have time to report all their cases and the MCTR staff has time to enter and review every case. On average, a hospital needs one hour to abstract one cancer case. After the MCTR receives the abstracts, they need one-half to one hour for each cancer case.

CDC's One-Stop Shop for Environmental Public Health Data
http://www.cdc.gov/nceh/tracking/resources_data.htm

Lou Olcott is the Biomonitoring Program Manager and Laboratory Training Coordinator for the Laboratory Services Bureau of the Department of Public Health and Human Services. She and Dr. Kammy Johnson work with the Rocky Mountain Biomonitoring Consortium, formed through a grant award from the Centers for Disease Control and Prevention in 2002. The proposal was to integrate the biomonitoring program among six states: Montana, Wyoming, Utah, Colorado, Arizona, and New Mexico. Each state has a member with an epidemiological background and laboratory background. All of the states in the consortium have geophysical commonalities and similar contamination issues. The RMBC includes large border states with sparse populations, few population centers, and a history of mining and smelting.

Biomonitoring assesses human exposure to toxic substances by laboratory measurement of these substances or their metabolites. The biomonitoring project will include establishment of baseline data for environmental toxins. The Consortium's primary objective is to increase existing laboratory capabilities and capacity within the region, and conduct biomonitoring as funds permit. The goal of the RMBC is to implement and expand the regional laboratory-based biomonitoring program to:

- develop laboratory capacity to monitor human exposure to environmental chemicals.
- determine the number of people in the RMBC region exposed to environmental chemicals, as well as the degree of their exposure.
- increase the capacity of the RMBC states and local health departments to deliver the environmental health services that help prevent disease resulting from exposure to toxic substances.
- work closely with local partners and other governmental entities to protect the health and wellbeing of our citizens.

Resource List

- Cancer Control Planet: cancercontrolplanet.cancer.gov
- Cancer in Montana Annual Report: www.cancer.mt.gov
- Behavior Risk Factor Surveillance System: www.dphhs.mt.gov/hpsd/BRFSS
- Environmental Public Health Tracking: www.dphhs.mt.gov/epht
- North American Association of Central Cancer Registries: www.naaccr.org
- American Cancer Society: www.cancer.org
- CDC's Cancer Prevention and Control Program: www.cdc.org/cancer
- The National Institutes of Health's National Cancer Institute (NCI): www.cancer.gov/cancer_information
- NCI Cancer Progress Reports: progressreport.cancer.gov
- National Toxicology Program: http://ntp-server.niehs.nih.gov

Data, Registry & Surveillance: What *You* Can Do

- **Support data collection** strategies. Participate in the BRFSS survey if called upon to do so.
- **Ask your legislators to support:**
  - the MCTR and EPHT.
  - acquisition of hospital discharge data for information about cancer in Montana.
- **Utilize the information** in Montana's cancer reports to understand and increase your knowledge about cancer and to reduce your risks.